

General

Guideline Title

Autism. Recognition, referral and diagnosis of children and young people on the autism spectrum.

Bibliographic Source(s)

National Institute for Health and Clinical Excellence (NICE). Autism. Recognition, referral and diagnosis of children and young people on the autism spectrum. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 51 p. (Clinical guideline; no. 128).

Guideline Status

This is the current release of the guideline.

The National Guideline Alliance (formerly the National Collaborating Centre for Women's and Children's Health) reaffirmed the currency of this guideline in April 2013.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Women's and Children's Health (NCC-WCH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Local Pathway for Recognition, Referral and Diagnostic Assessment of Possible Autism

A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.

The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:

- Improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C of the original guideline document)
- Making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- Supporting the smooth transition to adult services for young people going through the diagnostic pathway
- Ensuring data collection and audit of the pathway takes place.

In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:

- Paediatrician and/or child and adolescent psychiatrist
- Speech and language therapist
- Clinical and/or educational psychologist

The autism team should either include or have regular access to the following professionals if they are not already in the team:

- Paediatrician or paediatric neurologist
- Child and adolescent psychiatrist
- Educational psychologist
- Clinical psychologist
- Occupational therapist

Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a specialist health visitor or nurse, specialist teacher or social worker.

The autism team should have the skills and competencies to:

- Carry out an autism diagnostic assessment
- Communicate with children and young people with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them

Autism team members should:

- Provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- Decide on the assessment needs of those referred or when referral to another service will be needed
- Carry out the autism diagnostic assessment
- Share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate
- With parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member
- Offer information to children, young people and parents and carers about appropriate services and support

Provide a single point of referral for access to the autism team.

The autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including:

- Coexisting conditions such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders
- Looked-after children and young people

If young people present at the time of transition to adult services, the autism team should consider carrying out the autism diagnostic assessment jointly with the adult autism team, regardless of the young person's intellectual ability.

Recognising Children and Young People with Possible Autism

Consider the possibility of autism if there are concerns about development or behaviour, but be aware that there may be other explanations for individual signs and symptoms.

Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others.

When considering the possibility of autism and whether to refer a child or young person to the autism team, be critical about your professional competence and seek advice from a colleague if in doubt about the next step.

To help identify the signs and symptoms of possible autism, use tables 1–3 (see appendix C in the original guideline document). Do not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism.

When considering the possibility of autism, be aware that:

- Signs and symptoms should be seen in the context of the child's or young person's overall development
- Signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals
- When older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment
- It is necessary to take account of cultural variation, but do not assume that language delay is accounted for because English is not the family's first language or by early hearing difficulties
- Autism may be missed in children or young people with an intellectual disability
- Autism may be missed in children or young people who are verbally able
- Autism may be under-diagnosed in girls
- Important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system
- Signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness.

When considering the possibility of autism, ask about the child or young person's use and understanding of their first language.

Do not rule out autism because of:

- Good eye contact, smiling and showing affection to family members
- Reported pretend play or normal language milestones
- Difficulties appearing to resolve after a needs-based intervention (such as a supportive structured learning environment)
- A previous assessment that concluded that there was no autism, if new information becomes available

Discuss developmental or behavioural concerns about a child or young person with parents or carers, and the child or young person themselves if appropriate. Discuss sensitively the possible causes, which may include autism, emphasising that there may be many explanations for the child's or young person's behaviour.

Be aware that if parents or carers or the child or young person themselves have not suspected a developmental or behavioural condition, raising the possibility may cause distress, and that:

- It may take time for them to come to terms with the concern
- They may not share the concern

Take time to listen to parents or carers and, if appropriate, the child or young person, to discuss concerns and agree any actions to follow including referral.

Referring Children and Young People to the Autism Team

Refer children younger than 3 years to the autism team if there is regression in language or social skills.

Refer first to a paediatrician or paediatric neurologist (who can refer to the autism team if necessary) children and young people:

- Older than 3 years with regression in language
- Of any age with regression in motor skills

Consider referring children and young people to the autism team if you are concerned about possible autism on the basis of reported or observed signs and/or symptoms (see tables 1–3 in appendix C of the original guideline document). Take account of:

- The severity and duration of the signs and/or symptoms
- The extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- The impact of the signs and/or symptoms on the child or young person and on their family
- The level of parental or carer concern and, if appropriate, the concerns of the child or young person
- Factors associated with an increased prevalence of autism (see box below)
- The likelihood of an alternative diagnosis

Factors Associated with an Increased Prevalence of Autism

- A sibling with autism

- Birth defects associated with central nervous system malformation and/or dysfunction, including cerebral palsy
- Gestational age less than 35 weeks
- Parental schizophrenia-like psychosis or affective disorder
- Maternal use of sodium valproate in pregnancy
- Intellectual disability
- Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms
- Chromosomal disorders such as Down's syndrome
- Genetic disorders such as fragile X
- Muscular dystrophy
- Neurofibromatosis
- Tuberous sclerosis

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- Consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary
- Referring to another service. That service can then refer to the autism team if necessary.

Be aware that tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about signs and symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism. Also be aware that:

- A positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism
- A negative score does not rule out autism

When referring children and young people to the autism team, include in the referral letter the following information:

- Reported information from parents, carers and professionals about signs and/or symptoms of concern
- Your own observations of the signs and/or symptoms

When referring children and young people to the autism team, include in the referral letter the following information, if available:

- Antenatal and perinatal history
- Developmental milestones
- Factors associated with an increased prevalence of autism (see box above)
- Relevant medical history and investigations
- Information from previous assessments

Explain to parents or carers and, if appropriate, the child or young person, what will happen on referral to the autism team or another service.

If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting. If you remain concerned about autism, reconsider your referral decision.

If the parents or carers or if appropriate, the child or young person, prefer not to be referred to the autism team, consider a period of watchful waiting. If you remain concerned about autism, reconsider referral.

If a concern about possible autism has been raised but there are no signs, symptoms or other reasons to suspect autism, use professional judgment to decide what to do next.

After Referral to the Autism Team

When a child or young person is referred to the autism team, at least one member of the autism team should consider whether to carry out:

- An autism diagnostic assessment and/or
- An alternative assessment

Carry out an autism diagnostic assessment if there is regression in language or social skills in a child younger than 3 years.

Refer first to a paediatrician or paediatric neurologist (if this has not already happened) children or young people:

- Older than 3 years with regression in language

- Of any age with regression in motor skills

The paediatrician or paediatric neurologist can refer back to the autism team if necessary.

When deciding whether to carry out an autism diagnostic assessment, take account of the following (unless the child is under 3 years and has regression in language or social skills – see recommendation above):

- The severity and duration of the signs and/or symptoms
- The extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- The impact of the signs and/or symptoms on the child or young person and on their family or carer
- The level of parental or carer concern, and if appropriate the concerns of the child or young person
- Factors associated with an increased prevalence of autism (see box above)
- The likelihood of an alternative diagnosis

If there is insufficient information to decide whether an autism diagnostic assessment is needed, gather any available information from healthcare professionals. With consent from parents or carers and, if appropriate, the child or young person, seek information from schools or other agencies.

If there is uncertainty about whether an autism diagnostic assessment is needed after information has been gathered, offer a consultation to gather information directly from the child or young person and their family or carers.

Once it has been decided to carry out an autism diagnostic assessment, with consent from parents or carers (and the child or young person if appropriate):

- Seek a report from the pre-school or school if one has not already been made available
- Gather any additional health or social care information, including results from hearing and vision assessments

Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

Autism Diagnostic Assessment for Children and Young People

Start the autism diagnostic assessment within 3 months of the referral to the autism team.

A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

The autism case coordinator should:

- Act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- Keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- Arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- Gather information relevant to the autism diagnostic assessment (see recommendation in the previous section)

Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand.

Include in every autism diagnostic assessment:

- Detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- Details of the child's or young person's experiences of home life, education and social care
- A developmental history, focusing on developmental and behavioural features consistent with International Classification of Diseases, 10th Revision (ICD-10) or Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria (consider using an autism-specific tool to gather this information)
- Assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- A medical history, including prenatal, perinatal and family history, and past and current health conditions
- A physical examination
- Consideration of the differential diagnosis (see recommendation below)
- Systematic assessment for conditions that may coexist with autism (see recommendation below)
- Development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based

management plan, taking into account family and educational context

- Communication of assessment findings to the parent or carer and, if appropriate, the child or young person.

Perform a general physical examination and look specifically for:

- Skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light
- Signs of injury, for example self-harm (See 'Self-harm: the short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care' [NICE clinical guideline 16]. Available from www.nice.org.uk/guidance/CG16) or child maltreatment (see the NICE guideline [When to suspect child maltreatment](#) [NICE clinical guideline 89]).
- Congenital anomalies and dysmorphic features including macrocephaly or microcephaly.

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
 - Specific language delay or disorder
 - Intellectual disability or global developmental delay
 - Developmental coordination disorder (DCD)
- Mental and behavioural disorders:
 - Attention deficit hyperactivity disorder (ADHD)
 - Mood disorder
 - Anxiety disorder
 - Attachment disorders
 - Oppositional defiant disorder (ODD)
 - Conduct disorder
 - Obsessive compulsive disorder (OCD)
 - Psychosis
- Conditions in which there is developmental regression:
 - Rett syndrome
 - Epileptic encephalopathy
- Other conditions:
 - Severe hearing impairment
 - Severe visual impairment
 - Maltreatment
 - Selective mutism

Consider which assessments are needed to construct a profile for each child or young person, for example:

- Intellectual ability and learning style
- Academic skills
- Speech, language and communication
- Fine and gross motor skills
- Adaptive behaviour (including self-help skills)
- Mental and emotional health (including self-esteem)
- Physical health and nutrition
- Sensory sensitivities
- Behaviour likely to affect day-to-day functioning and social participation
- Socialisation skills

If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider:

- Gathering additional information from other sources and/or
- Carrying out further autism-specific observations in different settings, such as the school, nursery, other social setting or at home.

Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-IV criteria.

Do not rely on any autism-specific diagnostic tool alone to diagnose autism.

Be aware that in some children and young people there may be uncertainty about the diagnosis of autism, particularly in:

- Children younger than 24 months
- Children or young people with a developmental age of less than 18 months
- Children or young people for whom there is a lack of available information about their early life (for example some looked-after or adopted children)
- Older teenagers
- Children or young people with a complex coexisting mental health disorder (for example ADHD, conduct disorder, a possible attachment disorder), sensory impairment (for example severe hearing or visual impairment), or a motor disorder such as cerebral palsy

Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services.

If the outcome of the autism diagnostic assessment clearly indicates that the child or young person does not have autism, consider referring them to appropriate services based on their profile.

Consider whether the child or young person may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals:

- Mental and behaviour problems and disorders
 - ADHD
 - Anxiety disorders and phobias
 - Mood disorders
 - Oppositional defiant behaviour
 - Tics or Tourette syndrome
 - OCD
 - Self-injurious behaviour
- Neurodevelopmental problems and disorders:
 - Global delay or intellectual disability
 - Motor coordination problems or DCD
 - Academic learning problems, for example in literacy or numeracy
 - Speech and language disorder
- Medical or genetic problems and disorders:
 - Epilepsy and epileptic encephalopathy
 - Chromosome disorders
 - Genetic abnormalities, including fragile X
 - Tuberous sclerosis
 - Muscular dystrophy
 - Neurofibromatosis
- Functional problems and disorders:
 - Feeding problems, including restricted diets
 - Urinary incontinence or enuresis
 - Constipation, altered bowel habit, faecal incontinence or encopresis
 - Sleep disturbances
 - Vision or hearing impairment

Be aware that in children and young people with communication difficulties it may be difficult to recognise functional problems or mental health problems.

After the Autism Diagnostic Assessment

If there is uncertainty after the autism diagnostic assessment about the diagnosis, consider keeping the child or young person under review, taking into account any new information.

If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary):

- Continued uncertainty about the diagnosis
- Disagreement about the diagnosis within the autism team
- Disagreement with parents or carers or, if appropriate, the child or young person, about the diagnosis
- A lack of local access to particular skills and competencies needed to reach a diagnosis in a child or young person who has a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem
- A lack of response as expected to any therapeutic interventions provided to the child or young person

During the autism diagnostic assessment, consider any potential risk of harm to, and from, the child or young person and take appropriate action.

Medical Investigations

Do not routinely perform any medical investigations as part of an autism diagnostic assessment, but consider the following in individual circumstances and based on physical examination, clinical judgment and the child or young person's profile:

- Genetic tests, as recommended by your regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability
- Electroencephalography if there is suspicion of epilepsy (see the NGC summary of the NICE guideline [The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care](#) [NICE clinical guideline 137]).

Communicating the Results from the Autism Diagnostic Assessment

After the autism diagnostic assessment discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached.

Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.

For children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain:

- What autism is
- How autism is likely to affect the child or young person's development and function

Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn.

Share information, including the written report of the diagnostic assessment, with the GP.

With parental or carer consent and, if appropriate, the consent of the child or young person, share information with key professionals involved in the child's or young person's care, including those in education and social care.

With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.

For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the conclusions of the assessment and the implications for the child or young person).

For children and young people with a diagnosis of autism, discuss with parents or carers the risk of autism occurring in siblings and future children.

Information and Support for Families and Carers

Provide individual information on support available locally for parents, carers, children and young people with autism, according to the family's needs. This may include:

- Contact details for:
 - Local and national support organisations (who may provide, for example, an opportunity to meet other families with experience of autism, or information about specific courses for parents and carers and/or young people)
 - Organisations that can provide advice on welfare benefits
 - Organisations that can provide information on educational support and social care
- Information to help prepare for the future, for example transition to adult services

Clinical Algorithm(s)

An autism care pathway is provided in the Quick Reference Guide (see the "Availability of Companion Documents" field).

Scope

Disease/Condition(s)

Autism spectrum disorders (autism)

Note: The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) and have a significant impact on function. The over-arching category term used in ICD-10 and DSM-IV is pervasive developmental disorder (PDD), a term now used synonymously with autism spectrum disorder (excluding Rett's syndrome); it is a behaviourally defined group of disorders, which is heterogeneous in both cause and manifestation.

For clarity and consistency, in this guideline the term 'autism' is used throughout, in keeping with the use of 'autism' in recent Department of Health, National Audit Office and Public Accounts Committee documents. However in this guideline 'autism' refers to 'autism spectrum disorders.'

Guideline Category

Counseling

Diagnosis

Evaluation

Clinical Specialty

Family Practice

Neurology

Pediatrics

Psychiatry

Psychology

Speech-Language Pathology

Intended Users

Advanced Practice Nurses

Health Care Providers

Nurses

Occupational Therapists

Patients

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

To offer best practice advice on the initial recognition, referral and diagnosis of children and young people with autism

Target Population

Children and young people on the autism spectrum from birth up to 19 years and their parents/carers

Interventions and Practices Considered

1. Setting up a local autism multi-agency strategy group for recognition, referral, and diagnostic assessment of possible autism
2. Recognizing signs and symptoms of autism in children and young people
3. Discussing developmental or behavioural concerns about a child or young person with parents or carers
4. Referring children and young people to the autism team
5. Referral to a paediatrician or paediatric neurologist when appropriate
6. Performing an autism diagnostic assessment and/or an alternative assessment
7. Appointing a case coordinator for each child who is to have an autism diagnostic assessment
8. Sharing and communicating information about the outcome of the autism diagnostic assessment with parents/caregivers and the child
9. Performing a general physical examination
10. Consideration of differential diagnosis including other neurodevelopmental and mental health disorders
11. Diagnosis of autism based on International Classification of Disease, 10th Revision (ICD-10) or Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria
12. Steps to take if there is uncertainty of an autism diagnosis (e.g., keeping child under continued review, referral for second opinion)
13. Genetic testing or encephalography when appropriate
14. Providing information and support to parents and families

Major Outcomes Considered

- Diagnostic accuracy (sensitivity, specificity) of clinical and other features for the recognition of autism spectrum disorders (ASD)
- Diagnostic accuracy of biomedical investigations in ASD
- Identification of coexisting conditions
- Health-related quality of life, measured in quality-adjusted life years (QALYs)

Methodology

Methods Used to Collect/Select the Evidence

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Women's and Children's Health (NCC-WCH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Original Guideline

The Guideline Development Group (GDG) formulated clinical questions (see Appendix D in the full version of the original guideline document) from the scope and prepared a protocol for each review question (see Appendix E in the full version of the original guideline document). These

formed the starting point for the subsequent evidence reviews. The GDG was supported in the development of the clinical questions and protocols by the NCC-WCH technical team.

Published evidence was identified by systematic searches of the databases for the evidence. Reviews of the evidence published from 1990 to 11 October 2010 were undertaken by the NCC-WCH technical team. A search strategy designed to cover all the autism spectrum disorders was developed in the Medical Literature Analysis and Retrieval System Online (MEDLINE) database before being translated for use in the remaining databases, including Excerpta Medica database (EMBASE), the Cochrane Library Database, PsycINFO and Cumulative Index to Nursing and Allied Health Literature (CINAHL). Three educational databases were subsequently searched: ERIC, the British Educational Index and the Australian Educational Index. Studies of children or young people who did not meet the criteria for autism spectrum disorders were excluded from the guideline.

Search strategies combined a combination of MeSH headings and keyword searches including abbreviations. Searches were restricted to human studies and English language only; publications in languages other than English were not appraised. Methodological filters were not applied. The strategy was to undertake a broad search to identify all the evidence relating to autism spectrum disorders, rather than individual searches for every clinical question. The results were then sifted into individual questions as outlined below.

There was no systematic attempt to search grey literature (conferences, abstracts, theses and unpublished trials). Hand searching of journals not indexed on the database was not undertaken. Reference lists of included studies or reviews for additional references were not checked. Full details of the systematic searches, including the sources searched and the search strategies, are presented in Appendix F of the full version of the original guideline document. Although the condition-based search strategy generated a very large set of records, the information scientists considered this was the best method of developing a comprehensive and sensitive strategy in this subject area.

The results of the searches were incorporated into four reference manager databases alphabetised according to author (A-D, E-K, L-R and S-Z). In total there were 47,255 references. Each of these databases were then de-duplicated and weeding was performed to remove references unlikely to contain research data, including book reviews, book chapters and letters. Records not related to the subject area were also screened out at this stage, leaving a total database of 20,633 citations.

Two researchers then conducted a more stringent weeding excluding citations that were not relevant to this guideline (citations dealing with vaccinations, treatments or management of autism spectrum disorders) resulting in 5173 in the database. These citations were screened and allocated to one of the ten clinical questions and the researchers dealing with each question ordered citations for or exclusion. This resulted in 1215 citations being considered and 899 being ordered for the ten clinical questions.

The electronic searches were re-run in June 2010 and in Oct 2010 and another 5,154 references for weeding were identified. After following the stages outlined above, a total of 48 extra papers were ordered. The final cut-off date for searches was 11 October 2010. A total of 925 articles were examined in full text and of these 185 papers are included in the guideline.

2013 Reaffirmation

Searches

The literature was searched to identify studies and reviews relevant to the scope. Searches were conducted of the following databases, covering the dates 17 August 2009 (the end of the search period of NICE clinical guideline 128) to 29 October 2012:

- Cochrane Database of Systematic Reviews (CDSR)
- Cochrane Central Register of Controlled Trials (CENTRAL)
- CINAHL
- Database of Abstracts of Reviews of Effects (DARE)
- EMBASE
- Health Technology Assessment (HTA) database
- MEDLINE
- National Health Service (NHS) Economic Evaluation Database (EED)
- PsycINFO

Table 1 of the Evidence Update (see the "Availability of Companion Documents" field) provides details of the MEDLINE search strategy used, which was adapted to search the other databases listed above. The abbreviation ASD (autism spectrum disorder) was removed from the search for this evidence update because of a high number of irrelevant results (for example ASD meaning atrial septal defect). The search strategy was used in conjunction with validated Scottish Intercollegiate Guidelines Network search filters for randomised controlled trials (RCTs), systematic reviews, observational studies and diagnostic test accuracy studies.

Figure 1 of the Evidence Update provides details of the evidence selection process.

Number of Source Documents

Original Guideline

A total of 985 articles were examined in full text and of these 185 papers are included in the guideline.

2013 Reaffirmation

A search was conducted for new evidence from 17 August 2009 to 29 October 2012. A total of 3,626 pieces of evidence were initially identified. Following removal of duplicates and a series of automated and manual siffs, 25 items were selected for the evidence update.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Initial Study Quality Ratings

Quality	Design
High	Randomised controlled trials (RCTs)
Low	Controlled observational studies
Very low	Uncontrolled observational studies

Methods Used to Analyze the Evidence

Meta-Analysis

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Women's and Children's Health (NCC-WCH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Original Guideline

Reviewing and Synthesising the Evidence

Evidence relating to clinical effectiveness was reviewed and synthesised according to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach (see <http://www.gradeworkinggroup.org/index.htm>). Evidence profiles were used to summarise the quality of the evidence and the outcome data for each important clinical outcome. The initial quality of evidence was rated according to study design (see the "Rating Scheme for the Strength of the Evidence" field) as advised by NICE during the review process.

When using data from the cases in a case-control study, the study was classified as 'uncontrolled observational study' rather than 'controlled observational study.'

Checklists were used to quality rate the studies as follows:

- A quality assessment tool for diagnostic accuracy studies (QUADAS) checklist was used for diagnostic accuracy or predictive accuracy

studies.

- A Critical Appraisal Skills Programme (CASP) checklist for cohort (items 3, 4, 5, 6 and 7) was used for epidemiological /descriptive studies (available from <http://www.caspuk.net/>).
- The NICE checklist for qualitative studies (available from <http://www.nice.org.uk/niceMedia/pdf/GuidelinesManualAppendixH.pdf>) was used for qualitative studies.

One exception to this was the assessment of uncontrolled observational studies which were all graded as very low quality. It should be noted that the GRADE profile manual was revised during the development of this guideline. However for consistency this guideline has continued to use the version of the manual that was available at the beginning of development (version 3.1) which stated that uncontrolled observational studies should be graded as low quality. As such, the uncontrolled observational studies included in this guideline were not subjected to any quality analysis in accordance and have not been appraised in terms of 'limitations', 'inconsistency' and 'indirectness', as their quality was pre-defined. This has been made explicit in evidence profiles containing uncontrolled observational studies by inserting 'Not used' under each quality criteria heading.

For all other study designs, once study quality was determined they were then downgraded according to the following criteria: limitations, indirectness, inconsistency and imprecision. If one of these criteria could be applied to the study, this was considered to represent some concern, and if two or more criteria could be applied then this was considered as a serious concern. Where criteria could not be used (for example 'inconsistency' if there was only one study) then 'NA' (not applicable) was inserted into the evidence profile below the appropriate heading.

Data Extraction and Reporting

Quantitative Studies

Clinical evidence for individual studies was extracted into evidence tables (see Appendix H in the full version of the original guideline document) and, where possible, quantitative synthesis (meta-analysis) was carried out. Results from each study are presented in GRADE evidence profiles.

The supporting evidence statements report the outcomes from each evidence profile that met the Guideline Development Group (GDG) agreed levels of accuracy or prevalence. For reviews of prevalence data, findings were discussed with the GDG and only those variables (based on evidence and consensus) are reported in the evidence statements.

Qualitative Studies

Evidence of the views of children, young people and parents/carers of their experience was extracted from individual studies and placed in evidence tables, and summarised in modified GRADE evidence profiles. In order to best reflect children's and parents' opinions, as well as to avoid the risk of information loss or distortion, themes are reported in the modified GRADE evidence profiles instead of outcomes. These themes are supported by individual verbatim quotations from the included studies. The supporting evidence statements report on the outcomes from each evidence profile.

Refer to sections 2.6.4-2.6.6 of the full version of the original guideline document for additional information on methodological approaches, summary statistics for diagnostic/predictive accuracy, and other summary statistics used.

2013 Reaffirmation

An Evidence Update Advisory Group (EUAG), comprising topic experts, reviewed the prioritised evidence obtained from the literature search and provided their opinion on whether the new evidence may have a potential impact on the current guidance (see the "Availability of Companion Documents" field).

Methods Used to Formulate the Recommendations

Expert Consensus

Informal Consensus

Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Collaborating Centre for Women's and Children's Health (NCC-WCH) on behalf of the National Institute for Health and Clinical Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Original Guideline

Evidence to Recommendations

For each clinical question, recommendations are derived using, and linked explicitly to, the evidence that supported them. In the first instance, informal consensus methods are used by the Guideline Development Group (GDG) to agree clinical and, where appropriate, cost-effective evidence statements.

Statements summarising the GDG's interpretation of the clinical and economic evidence and any extrapolation (including economic modelling) from the evidence used to form recommendations were also prepared to ensure transparency in the decision-making process. Recommendations were only made on the basis of expert opinion including consideration of the health economic issues when no evidence was available based on the inclusion criteria specified in the review protocol.

In areas where no substantial evidence was identified, the GDG considered other evidence-based guidelines and consensus statements and then used these with the GDG members' collective experience to identify good practice. The GDG also identified areas where evidence to answer its clinical questions was lacking completely and used this information to draft recommendations for future research. The GDG did not undertake formal consensus methods, but, in the face of poor evidence or absence of evidence, reached a consensus through discussion during face to face GDG meetings and in subsequent email correspondence. Bias was minimised by ensuring that all voices in the GDG were heard and contributions listened to. All the GDG members agreed with the recommendations, not just a majority.

The GDG selected the key priorities for implementation by consensus at a GDG meeting based on the following criteria outlined in the *NICE Guidelines Manual 2009*:

- Have a high impact on patients' outcomes that are important to patients
- Have a high impact on reducing variation in care and outcomes
- Lead to a more efficient use of National Health Service resources
- Promote patient choice and equality.

The GDG gave high priority to recommendations that, when implemented, would mean patients reach critical points in the care pathway more quickly.

2013 Reaffirmation

The 2013 Evidence Update was used as the primary source of evidence for the 2014 surveillance decision to not update the guideline (see the "Availability of Companion Documents" field).

Rating Scheme for the Strength of the Recommendations

Not applicable

Cost Analysis

Health Economics

An economic evaluation aims to integrate data on benefits, ideally in terms of quality adjusted life years (QALYs), harms and cost of alternative options. For a lifelong social communication disorder such as autism spectrum disorders (ASD), relevant outcomes for economic evaluation of the diagnostic process are very hard to identify and even more difficult to quantify (see Chapter 10 in the full version of the original guideline for a more detailed explanation). For this reason it was anticipated that the health economic analysis for this guideline would be very limited. A health economic plan was agreed which included an economic analysis of specific diagnostic strategies and biomedical tests if robust evidence of diagnostic accuracy could be identified. Due to the lack of evidence identified in the reviews, no economic modelling was undertaken.

Due to the lack of data to develop health economic analysis, descriptions of resource use were gathered from five different ASD diagnostic services around the country of resource use in services that the guideline development group (GDG) believed were examples of good current practice; that is, which adhered to many of the important principles highlighted in this guideline including multidisciplinary, a dedicated ASD team, a clear ASD diagnostic pathway, and good communication and support for children and families during diagnosis. These were written up as service descriptions.

Even though health economic analysis could not be undertaken, every 'Evidence to recommendation' includes the GDG's considerations of the resource use, cost and benefits of specific recommendations. These considerations are not supported by externally verifiable evidence of cost effectiveness but represent the GDG's views and show how the GDG members weighed up the likely costs and benefits for the decisions they made that had an impact on resource use. The purpose of this is to increase the transparency for the GDG's recommendations where no evidence could be identified.

See the 'Evidence to Recommendation' sections of the full version of the original guideline, which includes the GDG's considerations of the resource use, cost and benefits of specific recommendations.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

The guideline was validated through two consultations.

1. The first draft of the guideline (the full version of the guideline, National Institute for Health and Clinical Excellence [NICE] guideline and Quick Reference Guide) were consulted with Stakeholders and comments were considered by the Guideline Development Group (GDG).
2. The final consultation draft of the full version of the guideline, the NICE guideline and the Information for the Public were submitted to stakeholders for final comments.

The final draft was submitted to the Guideline Review Panel for review prior to publication.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

There are benefits in establishing the nature of any developmental or behavioural disorder. Many families and carers find the process helpful, and early recognition can avoid delayed diagnosis. Even when children and young people do not have autism, if there are developmental or behavioural concerns, an evaluation of their condition is beneficial as they can be directed to other appropriate pathways.

Particular examples of how a diagnosis can enable the child or young person and their family or carers include:

- Access to information, services and support
- Emotional benefits
- Appropriate support from education, healthcare and social care services
- Recognition of coexisting conditions.

Refer to the sections titled "Trade-off between clinical benefits and harms" in the full version of the original guideline document for more information.

Potential Harms

- The Guideline Development Group (GDG) recognised that a decision to refer to the autism team might carry with it a risk of possible subsequent incorrect diagnosis of autism. This could have negative consequences for the children, young people and their families. It was therefore important that this guideline should provide recommendations to establish an autism diagnosis as accurately as possible. Overall, however, the GDG considered that this potential harm was outweighed by the benefits of recognition.
- Referral for an autism evaluation might be distressing for parents or carers, or even unacceptable to them and/or the child or young person. For that reason, the GDG emphasised the importance of careful discussion and involvement of the parents, carers and, where appropriate, the child or young person in the process, while keeping the child's or young person's interests central to the decision-making process.

Refer to the sections titled "Trade-off between clinical benefits and harms" in the full version of the original guideline document for more information.

Qualifying Statements

Qualifying Statements

- This guidance represents the view of the National Institute for Health and Clinical Excellence (NICE), which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.
- Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

Implementation of the Guideline

Description of Implementation Strategy

The National Institute for Health and Clinical Excellence (NICE) has developed tools to help organisations implement this guidance (see <http://guidance.nice.org.uk/CG128> ; see also the "Availability of Companion Documents" field).

Key Priorities for Implementation

The following recommendations have been identified as priorities for implementation.

Local Pathway for Recognition, Referral and Diagnostic Assessment of Possible Autism

A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.

The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:

- Improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C in the original guideline document)
- Making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- Supporting the smooth transition to adult services for young people going through the diagnostic pathway
- Ensuring data collection and audit of the pathway takes place.

In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:

- Paediatrician and/or child and adolescent psychiatrist

- Speech and language therapist
- Clinical and/or educational psychologist

The autism team should either include or have regular access to the following professionals if they are not already in the team:

- Paediatrician or paediatric neurologist
- Child and adolescent psychiatrist
- Educational psychologist
- Clinical psychologist
- Occupational therapist

Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a specialist health visitor or nurse, specialist teacher or social worker.

Provide a single point of referral for access to the autism team.

Autism Diagnostic Assessment for Children and Young People

A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

Include in every autism diagnostic assessment:

- Detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- Details of the child's or young person's experiences of home life, education and social care
- A developmental history, focusing on developmental and behavioural features consistent with International Classification of Disease, 10th Revision (ICD-10) or Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria (consider using an autism-specific tool to gather this information)
- Assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- A medical history, including prenatal, perinatal and family history, and past and current health conditions
- A physical examination
- Consideration of the differential diagnosis
- Systematic assessment for conditions that may coexist with autism
- Development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- Communication of assessment findings to the parent or carer and, if appropriate, the child or young person

Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
 - Specific language delay or disorder
 - Intellectual disability or global developmental delay
 - Developmental coordination disorder (DCD)
- Mental and behavioural disorders:
 - Attention deficit hyperactivity disorder (ADHD)
 - Mood disorder
 - Anxiety disorder
 - Attachment disorders
 - Oppositional defiant disorder (ODD)
 - Conduct disorder
 - Obsessive compulsive disorder (OCD)
 - Psychosis
- Conditions in which there is developmental regression:
 - Rett syndrome
 - Epileptic encephalopathy
- Other conditions:
 - Severe hearing impairment

- Severe visual impairment
- Maltreatment
- Selective mutism

Communicating the Results from the Autism Diagnostic Assessment

With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.

Implementation Tools

Audit Criteria/Indicators

Chart Documentation/Checklists/Forms

Clinical Algorithm

Patient Resources

Quick Reference Guides/Physician Guides

Resources

Slide Presentation

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

National Institute for Health and Clinical Excellence (NICE). Autism. Recognition, referral and diagnosis of children and young people on the autism spectrum. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 51 p. (Clinical guideline; no. 128).

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2011 Sep (reaffirmed 2013 Apr)

Guideline Developer(s)

National Guideline Alliance - National Government Agency [Non-U.S.]

Source(s) of Funding

National Institute for Health and Clinical Excellence (NICE)

Guideline Committee

Guideline Development Group

Composition of Group That Authored the Guideline

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Financial Disclosures/Conflicts of Interest

All Guideline Development Group (GDG) members and external advisers potential and actual conflicts of interest were recorded on declaration forms provided by the National Institute for Health and Clinical Excellence (NICE) (summarised in Appendix B of the full version of the original guideline document). None of the interests declared by GDG members constituted a material conflict of interest that would influence recommendations developed by the GDG.

Guideline Status

This is the current release of the guideline.

The National Guideline Alliance (formerly the National Collaborating Centre for Women's and Children's Health) reaffirmed the currency of this guideline in April 2013.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Available from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#) .

Availability of Companion Documents

The following are available:

- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. Full guideline. London (UK): National Collaborating Centre for Women's and Children's Health; 2011 Sep. 296 p. (Clinical guideline; no. 128). Available from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#) .
- Autism diagnosis in children and young people. Evidence update. London (UK): National Institute for Clinical Excellence (NICE); 2013 Apr. 36 p. (Evidence update; no. 40). Available from the [NICE Web site](#) .
- Surveillance review consultation document. 4-year surveillance review of CG128: autism: recognition, referral and diagnosis of children and young people on the autism spectrum. London (UK): National Institute for Clinical Excellence (NICE); 2014 Jul. 54 p. Available from the [NICE Web site](#) .
- Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum. Quick reference guide. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 24 p. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism in children and young people. NICE Pathways. (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Oct. Various pages. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. Baseline assessment. Implementing NICE guidance. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. Clinical case scenarios for professionals working with children and young people. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 60 p. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. Costing statement. Implementing NICE guidance. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 12 p. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. Audit tool. Implementing NICE guidance. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. Audit support. Implementing NICE guidance. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 8 p. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism: Recognition, referral and diagnosis. Implementing NICE guidance. Slide set. London (UK): National Institute for Health and Clinical Excellence; 2011 Sep. 31 p. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- Autism in children and young people. Signs and symptoms tables. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. (Clinical guideline; no. 128). Available from the [NICE Web site](#) .
- The guidelines manual 2009. London (UK): National Institute for Health and Clinical Excellence (NICE); 2009 Jan. Available from the [NICE Archive Web site](#) .

Patient Resources

The following is available:

- Autism in children and young people. Understanding NICE guidance. Information for people who use NHS services. London (UK): National Institute for Health and Clinical Excellence (NICE); 2011 Sep. 12 p. (Clinical guideline; no. 128). Available from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#) .

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC Status

This NGC summary was completed by ECRI Institute on January 23, 2012. The currency of the guideline was reaffirmed by the developer in

April 2013 and the summary was updated by ECRI Institute on December 8, 2016.

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